

Maternal and Child Health Needs Assessment Parents of Children with Special Health Care Needs



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INTRODUCTION



As set forth by the Maternal and Child Health Block Grant, the Family and Community Health Bureau is conducting a needs assessment of the maternal and child health population in Montana. This project is designed to identify the health needs of infants, children, and women of childbearing age.

This report presents observations and analyses based on confidential focus groups conducted with parents of children with special health care needs (CSHCN). The Montana Family and Community Health Bureau commissioned external partners, Sofia Warden and Colleen Roylance of Health Improvement Team, LLC to moderate the five focus groups in this study. These focus groups were held between November 2009 and January 2010 in five locations throughout Montana: Billings, Hamilton, Miles City, Missoula, and the Blackfeet Reservation. Focus group sessions lasted approximately 90 to 120 minutes and were audiotaped.

CAUTION

Focus group studies are conducted with small, carefully screened sample populations. Generally participants are not randomly selected; results may not be representative of the general population. Focus group research should be viewed as exploratory. The following observations are made from the limited context of these focus groups and should not be used as a substitute for quantitative research.

PARTICIPANT DEMOGRAPHICS

Child's Gender

Male	36	61%
Female	23	39%

Child's Age

Infant-5 years	22	39%
6-10 years	19	34%
11-14 years	8	14%
15-19 years	5	9%
20-29 years	2	4%

Does your child/children have dental insurance?

Yes	30	51%
No	29	49%

What is your child's race?

White	40	65%
Native American/Alaska Native	20	32%
Asian	0	0%
Black/African American	0	0%
Native Hawaiian/Pacific Islander	0	0%
Other	2	3%

Does your child/children have a primary/regular doctor?

Yes	55	92%
No	5	8%

In addition to your primary doctor, what are the other providers have your child/teen seen in the last year?

Specific Medical Specialist	39	21%
Dentist	36	19%
OT, PT, Speech Therapist	34	18%
Emergency Room	24	13%
Counselor/Mental Health	18	10%
Walk-in Clinic	14	8%
Public Health Clinic	13	7%
None	2	1%
Other (please specify)	5	3%

Primary source of your child's/children's insurance:

Healthy Montana Kids Plus (Medicaid)	39	65%
Private Insurance	10	17%
IHS/PHS	5	8%
Healthy Montana Kids (CHIP)	4	7%
None	2	3%

Does your child/children have vision insurance?

Yes	27	48%
No	29	52%

Is your child of Hispanic or Latino origin?

Yes	5	8%
No	55	92%

If so, who is your child's primary/regular doctor?

Pediatrician	40	67%
Family Practice Doctor	9	15%
Unknown	6	10%
Other (2-IHS, 1-Psychiatrist)	4	7%
Physician's Assistant	1	2%

What other (non-medical) services have your family/child used in the past year?

Special Education	33	25%
Family Support Services	29	16%
Case Management	22	12%
Social Services	17	9%
Respite	16	9%
None	10	5%
Other (please specify)	4	2%

MAIN THEMES

CHALLENGES AND CONCERNS

When asked what challenges parents face in their community, parents across all communities voiced similar challenges in finding the appropriate health care providers, treatment, and information for their children with special needs. These challenges are explained below in priority order.

1. Finding Treatment

Across all communities, parents said this is their biggest concern. This concern was defined as: the scarcity of local, competent providers, insufficient access to these providers, the lack of specialists in Montana, and the manner in which parents are treated by providers.

Scarcity of local, competent providers

The majority of parents in all communities reported this as the most frustrating part of caring for a child with special health care needs. Parents said it is very difficult *“finding health care professionals that understand and can help.”* These parents said they do not trust that their local physicians have up-to-date knowledge or the expertise necessary to treat their children. Parents in the smaller communities of the Blackfeet Reservation, Miles City and Hamilton appeared to experience this problem more severely than those in Missoula or Billings.

Insufficient access to local providers

In all communities, parents reported difficulties “because they don’t take Medicaid. Only on Wednesday between such and such a time. They’re not pleased to be giving me an appointment.” Participants included vision and dental providers as well as medical providers as being problematic. The Blackfeet Reservation participants said this is a particular problem since Indian Health Services provides children’s vision and dental services on a first-come, first-served basis limited to appointment openings on specified days.

Lack of specialists in Montana

Parents in all focus groups indicated the lack of specialists in Montana requires out-of-state travel. Many parents said this causes additional financial strain. Some parents said they see specialists that come to their community from a larger Montana city or from out of state. This poses its own problems of infrequent access and no help in crisis situations. One parent mentioned that coordination between all these *“separate entities”* creates the need for a *“medical home”*.

The manner in which providers treat parents

Parents voiced frustration with the manner in which providers treat them. Over half of the participants in these focus groups indicated providers discount what they say or *“don’t listen”*. For many parents on Medicaid, they feel they are not treated with respect and are *“looked down on”*.

2. Emotional Toll

All focus group participants responded that they experience emotional stress. For many, it is the “*daily grind*” of caring for a child with special health care needs. Several other parents mentioned the lack of support, “*respite care when I need it*” and limited knowledge of programs or services available. Parents reported feeling “*anger*” and “*pressure*”. Several parents said that, while the child can get help, finding care and coverage to treat the entire family is frustrating.

Participants caring for foster or adopted children reported that a lack of information and help from the Child Protective Services adds to their stress. Several parents on the Blackfeet Reservation and in Billings said they have not received the help they need for these children.

3. Insurance Coverage/Finances

All parents in all communities said they worry about their finances. Parents said they were frustrated by the “*cumbersome*” process of applying for Medicaid, the “*slim*” coverage it provides (including a lack of dental and vision coverage for many children), the difficulty getting payment, and the fear of being “*kicked off*”. One parent said, “*Everyone has to know every move you make and dime you spend. It’s humiliating.*” Several parents said that insurance coverage, especially Medicaid, “*takes away the choice of where to go*”.

For those few parents whose children are covered by private insurance, they said they pay too much “*out of pocket*”.

4. School

For parents with children in school, including preschool, many said they “*don’t receive enough help from our schools*”. Many parents said they “*get the feeling that the schools don’t want to deal with them*”. Several parents agreed that “*Professionals in school don’t take parental input. Special education teachers assume they know more or say ‘they have too many kids to keep track of the IEP of each one.’*”

5. Future of Their Children

Several parents expressed concern for their child’s future regarding ongoing services after high school. This was of special concern to a couple of parents in Hamilton whose children suffer with traumatic brain injury. The larger concern is for the well-being of the child if something were to happen to his/her parents. “*We’re older parents. If he lives to adulthood, what will his life be like?*”

Other parents expressed fear that without ongoing treatment, their children will be unable to become productive members of society. This relates to the belief that once their children reach adulthood, many public services will be discontinued. Others fear their future children becoming homeless or incarcerated for crimes due to lack of treatment for their special health care needs.

SERVICES

The following table lists resources mentioned during the focus groups and are not meant to be a complete list of available resources.

Agencies and Services				
Billings	Blackfeet Reservation	Hamilton	Miles City	Missoula
AWARE, Inc Mental Health Services Eagle Mount Parents, Let's Unite for Kids Family Support Groups Yellowstone Community Center Montana Care Services ABA Therapy STEP, Inc First Health Early Childhood Intervention Montana Transition Project Scottish Rite	Indian Health Services Po'ka Ranch Bureau of Indian Affairs Boarding School Family Groups Quality Life Concepts Opportunity Resources, Inc. Shodair Head Start Community Health Nurse	Ravalli Mental Health Denver's Children's Hospital	Youth Dynamics, Inc Developmental Education Assistance Program Action for Eastern Montana	Child Development Center Early Head Start Parents, Let's Unite for Kids Jadyn Fred Foundation Quality Life Concepts Women's Opportunity and Resource Development, Inc Children's Special Health Services Busy Hands Fun Center Public Health Nurse Early Childhood Intervention NAMI Scottish Rite University of MT Psychology Dept.

SURVEILLANCE AND INITIAL ASSISTANCE

When asked about the initial diagnosis and when that took place, participant responses ranged from "birth" to "we just started to notice things about his behavior". Several parents said it was very difficult to get a diagnosis and one parent said she "is still waiting".

Assistance at Time of Diagnosis

The help that was offered at the time of diagnoses varied. Across all communities, very few parents said they were offered the help or information they needed. Many said they were offered "none" or "very little (help)". The majority did research and found the help they needed on their own or through a support network of family and friends. One parent put it like this, "Plenty (of help), if you know where to go with the shuffle of doctors."

Services After Initial Diagnosis

Across all communities, parents were divided regarding the referrals they received for their children. Some parents voiced frustration with the lack of referrals, while other parents were frustrated by an overwhelming number of the same. For the majority of these parents, the frustration came from trying to find the one provider that could “*pinpoint*” the problem and provide solutions. Many parents said this process is time-consuming and costly because it usually involves travel. Not one parent in any community said he/she was satisfied with the coordination of all the referral services their child needs/receives.

TOP CONCERNS

When asked what they would change, the majority of parents in all communities expressed continuing frustration with the major concerns discussed in the Main Themes section of this report and are outlined below.

1. More help finding resources, services and information.
2. Help with finances, “*money*”.
3. More health care specialists in Montana.
4. More pediatricians and other providers that accept Medicaid.
5. Coordination of services, “*an advocate*”.
6. Disabled children should have services regardless of age.
7. Respect and courtesy from all professionals.
8. Medicaid coverage for all disabled children, children who are chronically ill or have life-threatening illnesses without regard to income.
9. Family therapy with a therapist who understands how disability affects the whole family.
10. More support from the school system.

CONCLUSION/RECOMMENDATIONS

Participants showed tremendous enthusiasm for participating in these focus groups. Many parents were thankful to have a forum in which they could voice their concerns. Participants in every focus group expressed how they learned about services and agencies from other participants. Several parents in each focus group exchanged contact information so they can continue to share information or initiate a support group.

These focus groups highlight some of the issues Montana families face when caring for children with special health care needs. Relevant findings and recurring themes have been raised in these focus groups and strategies should be identified for improvement. Some strategies to consider are to:

- Survey a larger number of parents of CSHCN to verify and analyze the qualitative results of these focus groups and identify other improvement opportunities.
- Set quantitative outcome goals to measure effectiveness of Maternal and Child Health Block Grant cycles.
- Plan and conduct a ‘road show’ throughout Montana to engage public health stakeholders (such as local health departments, state agencies, families, health plans, local public school systems). This ‘road show’ could utilize a PowerPoint presentation build around this report and discuss specific strategic planning and/or policy development.